Serious Case Review

Child O

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1 INTRODUCTION

1.1 This Serious Case Review (SCR) was conducted under the statutory guidance of Working Together to Safeguard Children 2013 (Working Together 2015 WT2015 has superseded this but this review was completed prior to that publication).

1.2 Child O is the subject of this Serious Case Review (SCR).

1.3 Child O died in 2012, after hanging himself in the barn at the remote rural home he shared with his father (FCO). Child O was 17 years old when he died. The Coroner concluded "[He] died as a consequence of his own actions whilst suffering from mental health problems and after consuming a substantial amount of alcohol".

1.4 Child O had an identical twin (BCO) and had one older sibling (SCO). Child O's history of contact with services in Cumbria and Northumbria is extremely complex.

1.5 This case was picked up in the legacy issues through a review of the application of the criteria for SCR's by the incoming Chair of the LSCB in May 2014 and it was considered that this tragic case did meet the criteria for a serious case review. The review was then commenced.

1.6 Working Together 2013 guidance is clear that serious case reviews are a part of the learning and improvement framework that all local safeguarding children boards must have in place to identify learning from cases in order that local and national practice to safeguard children can continuously improve.

1.7 The purpose of a SCR is to conduct "a rigorous, objective analysis of what happened and why, so that important lessons can be learnt and services improved to reduce the risk of future harm to children". To facilitate this Cumbria Local Safeguarding Children Board (LSCB) Case Review Subgroup developed terms of reference for the review.

1.8 Reviews therefore must seek to:

1.8.1 identify precisely who did what and the underlying reasons that led individuals and organisations to act as they did

1.8.2 understand practice from the point of view of the individuals and organisations involved at the time rather than using hindsight

1.8.3 be transparent about the way information is collected and analysed and

1.8.4 make use of relevant research and case evidence to inform the findings

1.9 The terms of reference cover the period from 2001 to June 2012

2 METHODOLOGY

2.1 The government has indicated that it supports changes recommended by Professor Eileen Munro that SCR's should be conducted using systems based learning methodology, such as that developed by Social Care Institute for Excellence (SCIE) and it was agreed that important learning could be gained by conducting a 'whole system' SCR in order to conceptualise how services routinely operate and to identify what is working well or where there are problematic areas.

2.2 The LSCB Case Review Subgroup recognised that the review would need to be as robust and transparent as the former SCR processes and should be measured by the extent to which it would make a difference and improve Cumbria's multi-agency safeguarding response.

2.3 The analysis in this report uses some elements of the framework developed by SCIE to present key learning within the context of local systems in Cumbria and in Northumbria. This also takes account of recent work that suggests that an approach of developing over prescriptive and SMART recommendations have limited impact and value in complex work such as safeguarding children. For example, a 2011 study of recommendations arising from serious case reviews 2009-2010, (Brandon, M et al), calls for a limiting of 'self-perpetuating and proliferation' of recommendations. Current thinking about how the learning from serious case reviews can be most effectively achieved is encouraging a lighter touch on making recommendations and simplifying action plans to implement them.

2.4 The SCR was designed and led by Clare Hyde MBE, independent reviewer, from The Foundation for Families (a not for profit Community Interest Company). Ms. Hyde developed a review model that would enable participants to consider the events and circumstances, which led up to the tragic death of Child O.

2.5 An Expert Leads Panel was convened of senior and specialist agency representatives to oversee the conduct and outcomes of the review.

2.6 The Panel agreed specific terms of reference that provided the key lines of enquiry for the SCR in addition to the terms of reference described in national guidance. The key lines of enquiry included:

2.6.1 How well the risks of significant isolation were recognised and understood?

2.6.2 Was the isolation of Child O (and his sibling) ever, in itself, considered neglectful or abusive?

2.6.3 How was the parenting capacity of Child O's parents assessed?

2.6.4 How well were the complex needs of Child O recognised, assessed and responded to?

2.6.5 Was a risk and need assessment carried out in respect of the circumstances of the whole family. Were there other opportunities for risk assessments which were missed? Multiple and dynamic risk issues and how risks are recognised, assessed and responded to.

2.6.6 How well information was shared, understood and responded to between agencies and across geographical boundaries

2.6.7 How well was Child O listened to and understood?

2.6.8 Multi-agency tolerance and understanding of risk, how do we escalate concerns?

2.7 The panel established the identity of services in contact with the family during the time frame agreed for the review.

2.8 The SCR aimed to provide an innovative 'whole system' approach involving key front line practitioners (and their line managers) who worked with Child O and adults of Child O's family in a learning event. In this way, Child O's 'story' was to be central to the Learning event. In preparation for the Learning event practitioners were asked to complete a chronology identifying key practice episodes and describing:

- What could / should have been done differently?
- What worked well and how was this evidenced?

Independence

2.9 An independent chair, Richard Simpson, Regional Manager, Barnardo's was appointed by the Safeguarding Children Board to chair the expert panel.

2.10 As previously stated, the lead reviewer was Clare Hyde, Director at The Foundation for Families. Clare has over twenty years' experience in

developing and delivering services for people and families with complex needs. She has been involved in a number of serious case reviews since 2012 and was a member of Baroness Corston's review team which was commissioned by the government following the deaths of 12 women in custody. Clare has held various operational and strategic roles and led the transformation of adult care programme in the Yorkshire and Humber region.

Serious Case Review Panel

2.11 The Expert Leads Panel met on

- 14 July 2014
- 20 October 2014
- 15 January 2015
- 4 February 2015
- 15 April 2015
- 12 October 2015

2.12 The overview report was ratified at the Local Safeguarding Children Board meeting in February 2016 and a further meeting of the expert leads panel was called in March 2016 to finalise the recommendations and action plan.

2.13 The panel comprised of:

Title	Organisation
Vice Chair of the LSCB	Independent Chair
Senior Manager	LSCB
Designated Nurse	Clinical Commissioning Group (CCG)
Lead General Practitioner (GP) for Safeguarding Children	CCG – Primary Care (Also representing CHOC)
Detective Superintendent	Cumbria Constabulary
Assistant Director	Children's Services
Team Manager (Child and Adolescent Mental Health Services (CAMHS))	Cumbria Partnership Foundation Trust (CPFT)
Deputy Named Nurse	North Cumbria University Hospital Trust(NCUHT)
Named Nurse, Safeguarding Children	NCUHT
General Advisor, Learning & Improvement Service	Children's Services
Senior Nurse (mental health)	Northumberland, Tyne and Wear Partnership Foundation Trust (NTW)
Co-ordinator	Newcastle Safeguarding Children Board
Safeguarding Practice Manager	North West Ambulance Service (NWAS)
Designated Nurse Safeguarding Children	Newcastle Clinical Commissioning Group

Title	Organisation
Head of Clinical Safety	NWAS
Network Manager	CPFT
Clinical Services Manager (CAMHS)	CPFT

Confidentiality

2.14 Working Together to Safeguard Children 2013 clearly sets out a requirement for the publication in full of the overview report from Serious Case Reviews:

"All reviews of cases meeting the SCR criteria should result in a report which is published and readily accessible on the LSCB's website for a minimum of 12 months. Thereafter the report should be made available on request. This is important to support national sharing of lessons learnt and good practice in writing and publishing SCRs. From the very start of the SCR the fact that the report will be published should be taken into consideration. SCR reports should be written in such a way that publication will not be likely to harm the welfare of any children or vulnerable adults involved in the case."[1]

Family involvement

2.15 Child O's family were notified of the review however initially FCO contacted the panel chair and advised him that the family members did not wish to contribute to the review process. In June 2015 however, FCO did meet with the Independent Chair and the LSCB Business Manager and was able to share his views about the engagement of services with the family during the timescale of this review.

2.16 Following the finalisation of the report, and just prior to publication the Lead Reviewer, the chair of the Expert Panel and Senior Manager - LSCB met with FCO and MCO to share the report and discuss publication.

2.17 MCO and FCO queried some specific elements of the initial and core assessment which led to some amendments being made to the assessments. It was also agreed between Children's Social Care (CSC) and FCO and MCO (on 15th February 2011) that the response to the queries and the subsequent amendments would be permanently attached to the assessments so that any professional accessing them would have a full 'picture'. This did not happen on every occasion and in their discussions with the Independent Chair of the Expert Leads Panel, the Lead Reviewer and the LSCB Senior Manager - MCO and FCO described how this added to their sense of despair and frustration.

2.18 The Expert Panel Members would like to thank FCO and MCO for participating in the review and note that their stated reason for doing so, is to

[1] Working Together to Safeguard Children 2013 p71

ensure that safeguarding practice improves for other children and young people.

Dissemination of learning

2.19 The learning from this review will be disseminated to safeguarding children board professionals via the Learning and Improvement sub group and the Communication and Engagement sub group with the aim of improving professional practice.

Race, Religion, Language and Culture

2.20 Child O was English speaking White British. Religion was not known to be a feature of his life. Child O and his family lived in rural isolation and MCO and FCO chose to educate both children at home for a long period of time which would have impacted upon their family culture and identity.

2.21 Child O was a twin and being part of a "twin unit" is a unique experience and the siblings were described as seeing themselves as one person. Their 'twin culture' was undoubtedly a significant factor in their lives.

3 BACKGROUND INFORMATION

3.1 The time scale for the review is unusually long as the expert panel believed that events which took place in 2005 were significant to the learning to be gained from the review. Key events from Child O's birth are also included and are described in brief below.

3.2 Child O was born in 1994 and was an identical twin. Child O and his sibling (BCO) lived with their mother (MCO) and their father (FCO) in Cumbria.

3.3 Child O and BCO attended two small village schools, one from 2000 until 2004 when the siblings transferred to a second primary school in the autumn of 2004 (they attended for one term only before they were withdrawn by their parents to be home educated).

3.4 MCO was aged 48 at the time of Child O's death and FCO was aged 52.

3.5 Nothing significant is recorded by Child O's GP until 2005 when the GP referred Child O and BCO to the Child and Adolescent Mental Health Service (CAMHS) as their parents were struggling to cope with their behaviour.

3.6 Also in 2005 Child O and BCO were removed from mainstream education and were educated at home by MCO.

Background information MCO and FCO

3.7 There is very little information known about MCO and FCO by health and other agencies.

3.8 There was however, consensus amongst the practitioners who had contact with MCO and FCO that they were, at times, challenging in their interactions with practitioners, and that this appeared to be in an attempt to protect Child O and BCO and manage their behaviour and their distress.

3.9 It is important to note that MCO and FCO asked their GP for advice and support in managing the behaviour of Child O and BCO in 2005 at around the time they removed the children from mainstream education.

3.10 The GP made a referral to CAMHS. A CAMHS psychologist and his colleague met with MCO and FCO on 27th June 2005. The discussion that took place gives an insight into the difficulties MCO and FCO were facing in parenting Child O and BCO.

3.11 MCO and FCO discussed ongoing difficulties regarding the children's education and refusal to cooperate with every day family activities or tasks. They stated that the boys have full blown tantrums if pushed to do anything and they were at a loss to know what to do with them. It was recorded that MCO reported that the boys 'absolutely hate human beings'. MCO and FCO were concerned that the boys would become more isolated and difficult to guide as they get older. It was reported that Child O could read but BCO could not which may result in their tendency to compensate for one another's weaknesses and strengths. MCO and FCO wanted to know to what extent the boys have control of their own behaviour. The psychologist was unsure how to answer parent's questions and suggested an appointment with Child O and BCO to try and engage and possibly carry out psychometric tests.

3.12 MCO experienced a significant loss in 2007 when her sister, Child O's aunt died in a tragic accident. MCO's sister also seems to have been a protective factor in the lives of the children and MCO identified this loss as significant in Child O's declining well -being.

Narrative and Summary of Child O's Contact with Services

3.13 There are more contacts with health (including A and E and secondary health care) practitioners, social care and others than are referred to in the following summary of professional contact with Child O and his family. This summary provides an account of the most significant events and decisions from the different services involved during the timeframe of the SCR. This summary

was used as a core element of the Learning Event and enabled practitioners to see the 'whole family' multi -agency involvement.

Child O's contact with Mental Health Services

3.14 Both Child O and BCO were referred to the Child and Adolescent Mental Health Service (CAMHS) in 2005 by their GP due to withdrawal from school by their parents and the twins having their own culture of behaviour and acting as a 'unit'. Child O was then aged 10.

3.15 Child O and BCO attended their first appointment with CAMHS on 13th July 2005. MCO and FCO also attended.

3.16 There was ongoing involvement with Child O and BCO by the CAMHS team between 2005 and 2006 when the children disengaged with the service as they were too distressed at the suggestion that they be seen by separate therapists for separate interventions. The children and/or their parents decided that they did not want further contact with CAMHS.

3.17 The CAMHS psychologist and colleague met again with MCO and FCO on 7th July 2008 following a further referral to CAMHS by their GP. This referral had been made because of MCO's concerns around the boys' reluctance for dental treatment. Eating behaviour patterns, educational progress and tests for the children were discussed and the psychologist planned to contact a Consultant Child and Adolescent Psychiatrist at Fairfield Hospital, Cumbria for a second opinion. There is no record of this contact being made until November 2009. Child O was then aged 14.

3.18 During a meeting on the 1st December 2008 with both parents and the CAMHS psychologist, MCO returned test (British Picture Vocabulary Scales) as she didn't think it was suitable regarding BCO's literacy skills. Both parents raised concerns about educational support and it was suggested that they contact the Children Missing Education Officer. Dental issues remained a concern with the children now refusing meals prepared by their parents or to eat from the same utensils for fear of contamination from sugar which would damage their teeth. MCO and FCO described feeling more controlled by the boys and found it difficult to see a way out. The CAMHS psychologist was unsure of how to proceed but suggested that the family be offered an appointment at the Family Therapy Clinic at Fairfield Hospital. It was left to MCO and FCO to make contact should they wish to pursue this referral.

3.19 Between 2008 and October 2009 there was ongoing involvement with MCO and FCO by the CAMHS team however neither Child O nor BCO were seen having refused contact.

3.20 In October 2009 Child O and BCO were referred by a Clinical Psychologist from Cumbria to the Regional Pervasive Disorders Service for a second opinion regarding whether their difficulties met the criteria for an Autism Spectrum Disorder.

3.21 On the 4th October 2009 a Clinical Psychologist from Northumberland Tyne and Wear met the family at home to plan the assessment process for the siblings with a further appointment agreed.

3.22 Between 2009 and January 2010, MCO reported to the GP, the CAMHS Clinical Psychologist and the Regional Pervasive Disorders Service that Child O's mental health was deteriorating, that he was depressed and that his life was ruled by anxieties and obsessions and that he had withdrawn almost completely and was in tears most of the time. MCO requested urgent help and was very distressed.

3.23 During this timescale repeated contacts were offered to the children but the parents were acting as intermediaries and Child O was never seen.

3.24 On 30th January 2010, Child O made a serious suicide attempt and Cumbria CAMHS involvement ended and he became an in-patient at Cumberland Infirmary Cumbria and then at a Specialist Children's Mental Health Hospital in Newcastle.

3.25 Child O was admitted to a Specialist Children's Mental Health Hospital at the request of his Clinical Psychologist from Cumbria. The Clinical Psychologist indicated that Child O would benefit from treatment independent of his twin brother. It was suggested that Child O, at the time had OCD and a heightened level of anxiety in relation to the management of tooth decay. The attempted suicide act was assessed as an impulsive act borne of desperation at the constant fear of contact with sugar. Child O was a patient at the Specialist Children's Mental Health Hospital between 9th March 2010 and 11th February 2011.

3.26 During this time a range of multidisciplinary assessments were undertaken including Autistic Spectrum Disorder assessment, Cognitive assessment, Obsessive Compulsive Disorder Assessment, Paediatric Neurology Assessment.

3.27 The formulation of these assessments identified that Child O had a diagnosis of Autistic Spectrum Disorder, a severe anxiety disorder consistent with Obsessive Compulsive Disorder and a Learning Disability.

3.28 Child O had a fixed belief and preoccupation about the need for full dental extraction to overcome the worries of coping with fear about pain to his teeth.

3.29 In April 2010 (Child O was then aged 16) an assessment of Child O's mental capacity was undertaken to identify if he could make the decision about whether he could have his healthy teeth removed. The assessment concluded that Child O lacked the capacity to make such a decision with a recommendation of further mental capacity assessments if his fixed belief regarding removal of all of his teeth remained.

3.30 It was considered by the assessing doctor that Child O had difficulty in quantifying realistically the tooth pain that may be experienced, that his judgement was clouded in part by the anxiety disorder and possibly his mood.

3.31 In June 2010 Child O and BCO were assessed in Newcastle by a Psychiatrist and Psychologist from the National CAMHS OCD Team from the Maudsley Hospital. This assessment had been requested by both NTW and Cumbria Healthcare.

3.32 The assessment concluded that both children met the criteria for OCD, however the OCD was relatively unusual in its nature and its presentation and was modified by the twins' underlying developmental difficulties. The children had more or less identical beliefs that their teeth would decay and rot if they encountered various substances including sugar, citrus etc. and undertook an extensive range of rituals and avoidances to counteract this belief. They were distressed by this fear and although each acknowledged to some extent that this was exaggerated they were committed in their belief that the only way to solve this would be to have their teeth removed. This lack of insight and concreteness needed to be seen in the context of it now having been established that both children had a learning disability as well as being on the autism spectrum.

3.33 The summary and plan formulated following this assessment stated that 'both children have a learning disability, autism and anxiety disorder consistent with Obsessive Compulsive Disorder (OCD). Child O is more severely affected having recently made a suicide attempt and continues to be withdrawn and depressed and may also have a more significant degree of learning disability, however the obsessions and preoccupations are identical. They have no peer group and have been very isolated in their local community and home schooled'.

3.34 The Management plan was comprehensive and required two approaches to be carried out in parallel to address educational issues and psychological treatment.

3.35 Child O was allocated a multi-disciplinary team to support him including a consultant psychiatrist, nursing staff, occupational therapists, psychologist, teachers, dietician, and external specialists.

3.36 Child O was an in-patient at the Specialist Children's Mental Health Hospital in Newcastle for almost 8 months. During that period he was placed on observations, fluid and diet balance charts were maintained and staff developed structured timetables of activities and education and therapy sessions.

3.37 On examination of the unit's records however it was noted that there was very little change in Child O's presentation. He sat on his bed in a hunched position, prepared and ate food in his room and was very reluctant to leave his room for education and therapy sessions.

3.38 Child O communicated via MCO (who stayed with him much of the time that he was an inpatient) and if he did speak directly it was in a very quiet voice. He continually expressed anxiety that staff were not supporting him in his request to have his teeth removed.

3.39 It was recorded that Child O and MCO felt that he had deteriorated since his admission.

3.40 Child O was initially discharged on 4th November 2010 on extended home leaves with an outreach therapeutic timetable. He was discharged to Tier 3 CAMHS Learning Disability Team (Newcastle). Additionally, an Educational Psychologist in Newcastle was undertaking an assessment of his educational needs.

3.41 On discharge Child O continued to live in Newcastle with his brother and his parents and was offered twice weekly individual clinical psychology appointments and declined to attend any. (It appears that Child O moved back to Cumbria with FCO in January 2011 although MCO and FCO stated that this was not a permanent move).

3.42 On 16th January 2011 Child O was assessed by an NTW Professor in Child and Adolescent Mental Health who identified that Child O had been unable to independently leave his new family home in Newcastle being totally reliant on his parents to manage day to day, he continued to refuse to eat with his family

or undertake any educational, therapeutic or leisure activities. He sat stationary on his bed and was said to become more anxious if he expected visitors. The lack of any apparent formal educational progress since the age of 10 indicated the severity of his needs and the intense degree of resistance that he imposed on himself and the family. Child O expressed a wish not to engage with the multi -disciplinary team and his parents would not go against his wishes.

3.43 In February 2011 a Clinical Psychologist (Newcastle) became the lead professional for Child O on his discharge from the Specialist Children's Mental Health Hospital.

3.44 A Clinical Psychological Interim Capacity Assessment dated 27th July 2011 summarised that Child O was seen 10 times between April and June 2011, the aim of the contacts were to get to know and understand him, and help with the multi-agency assessment of his capacity regarding his teeth extraction. Child O and his family found these sessions very difficult. Various assessments were carried out and some which had previously been done were repeated. The conclusion was that Child O's ability was within the normal range and he did have the cognitive capacity to understand what he was saying. He understood and was able to weigh up the risks about what he was told about having a full dental removal.

3.45 The psychologist felt he was rigid in his thoughts and in his belief about what would make a difference. He felt disappointed that whatever he had tried had not stopped the anxiety and worry and feels that may never go away.

3.46 The psychologist expressed concern as to how Child O could be sure that by having a total dental extraction would enable him to achieve his goals and it was suggested he start making some progress in setting goals to prove that change is possible.

3.47 Child O was seen again on four occasions between August 2011 and November 2011. It was noted that Child O had become less rigid in his eating rituals and had slightly increased his range of foods. FCO had noted an improvement in him and again he was deemed as having capacity at that time.

3.48 In October 2011 a request was made for a second opinion from a NTW Professor to a TEWV (Tees, Esk and Wear Valley NHS Trust) Psychiatrist in relation to a mental capacity assessment in relation to Child O's ability to consent to surgery to remove all his teeth.

3.49 NTW also sought legal advice regarding the issue of acquiescing to Child O's request for full teeth extraction.

3.50 The second opinion undertaken in December 2011 assessed that Child O did not have the capacity to make such a decision.

3.51 In January 2012 FCO was seen by the Clinical Psychologist (Newcastle) on his own and FCO indicated that Child O was making good progress and looking at how to move on and get a job, using the internet as well as having more conversations with him.

3.52 In January 2012 contact was made by NTW with Cumbria Children's Services due to concerns that Child O was drinking cola and eating sugar on a daily basis in an attempt to destroy his teeth. He had done so over a four month period causing significant damage to and removal of some teeth. Additional concerns were his social isolation, his reluctance to leave the home and neglect of basic health needs. An assessment carried out in August 2011 by the Clinical Psychologist in Newcastle indicated that he did not have a learning disability.

3.53 In January 2012 when Child O was informed that some of his teeth would have to be removed due to recent decay, he decided that he wanted to retain as many teeth as possible. At that time FCO stated to Child O's psychologist that Child O was 'doing his own therapy' and did not want any further involvement from Health agencies.

3.54 In February 2012 Child O was referred to Cumbria CAMHS (he was living in Cumbria with his father although his GP was recorded to be still in Newcastle and the permanence of his residency in Cumbria was disputed by MCO).

3.55 An appointment letter was sent by CAMHS on 7th March 2012 for appointment on 16th April 2012.

3.56 FCO attended this appointment alone and Child O was not seen. FCO reported that Child O was 'better' and that Child O did not want CAMHS involvement.

Child O's contact with Children's Services

3.57 The paramedics who responded to Child O when he attempted suicide in January 2010 made an immediate and detailed safeguarding referral to Children's Social Care. This referral described Child O as being small and under nourished and that he had serious previous self-harm scars which had not been noticed by MCO or FCO i.e. concerns of possible neglect, parental incapacity, physical signs (self -harm), behavioural signs and concerns about the environment.

3.58 The paramedics described bilateral wrist lacerations, bilateral scratch marks on his arms, possible old laceration scars (which FCO and MCO said they had not noticed) and he had a significant neck laceration.

3.59 The Social Worker (SW1) liaised with Child O's CAMHS worker and it was confirmed that Child O was viewed as extremely vulnerable and that a referral to an in-patient mental health setting was being made for him.

3.60 SW1 and the CAMHS worker agreed that SW1 would write to MCO and FCO and offer advice and support if required.

3.61 On 23rd February 2010, the CAMHs worker informed children's social care that a multi-agency planning meeting had been held. Child O was still an in-patient and there were significant concerns about Child O's suicide attempt and it was agreed that he required a residential facility to assess and undertake Tier 4 mental health work with him. The residential facility which was chosen dealt primarily with eating disorders and was not felt to be appropriate by MCO and FCO. The meeting was held to consider if discharge home was safe for Child O given the strong likelihood that he would attempt suicide again.

3.62 On 24th February 2010, Child O's case was allocated to a social worker (SW2) (SW1 had responded to the initial referral and had provided advice and information only).

3.63 On 4th March 2010, an initial social care assessment was carried out. It was recorded that Child O was due to be admitted to the Nuffield Clinic as an in-patient on 9th March 2010. Child O had already been assessed by the clinic as a suitable patient and was awaiting parental approval from MCO and FCO.

3.64 Further and ongoing assessments of Child O and a referral to the Maudsley Hospital specialist OCD centre was planned for later in 2010.

3.65 There was concern amongst the practitioners of the risk to Child O should parental consent be withheld due to the nature of Child O's previous suicide attempt and the risk that, despite parental supervision he might attempt suicide again.

3.66 It was further recorded that MCO and FCO had tried to manage the situation in their home environment and that agency involvement had been limited to CAMHS and the GP.

3.67 Children's Social Care and the School Improvement Team did not have any contact with Child O (or BCO) and FCO made it clear that he and MCO did not

want Children's Social Care involvement particularly as they viewed any small change in the children's environment as extremely harmful.

3.68 SW2 arranged a strategy meeting in accordance with child protection procedures to review how agencies could work together for Child O and BCO.

3.69 The strategy meeting was held on 10th March 2010 and the SW Team Manager expressed that she was very concerned about the welfare of Child O and BCO and that the risk of self- harm for both boys was high.

3.70 BCO had not been seen by any professional for some considerable time and it was not known what his thoughts or feelings were following Child O's suicide attempt.

3.71 It was also recorded that there was uncertainty about how MCO and FCO were managing the situation and that if they did not agree with professional advice and attempted to continue to manage the situation alone that this may have an adverse impact on Child O and BCO.

3.72 Actions recommended from the strategy meeting included:

3.72.1 Children's services to contact the paramedics to clarify the issue of locks on the children's bedroom doors.

3.72.2 To support MCO and FCO to understand professional concerns including further risks to the children.

3.72.3 Although there was an acknowledgement of the difficult situation MCO and FCO are in it was also agreed that they need to accept a negotiated treatment plan for Child O, BCO and a support for themselves as carers.

3.72.4 If MCO and FCO had difficulty in accepting this then Children's Services would seek legal advice on the welfare issues of the children.

3.72.5 SW2 agreed to provide an update following a further assessment of Child O and BCO by mental health practitioners in Newcastle.

3.72.6 On 30th March 2010, SW3 was allocated Child O's case and undertook a core assessment on 30th July 2010 (there is no explanation given in the agency records as to why there was a change in social worker).

3.73 The outcome of the core assessment was that Child O would be transferred to the Learning Difficulties and Disabilities Team as he was still living in Cumbria and required specialist ongoing support.

3.74 FCO and MCO would also be provided with support and it was acknowledged that this was a very difficult time for them.

3.75 The Specialist Children's Mental Health Hospital would continue to provide the necessary treatment and assessment of Child O (and BCO) and the Maudsley Hospital would provide additional expertise and resources.

3.76 On 5th August 2010 SW4 (Learning Difficulties and Disabilities Team) was allocated the case and remained the children's social worker until 19th November 2010 when the case was closed.

3.77 It is unclear what contact SW4 had with the family between August and November but it was noted that the services the Learning Difficulties and Disabilities Team could offer were not felt to be suitable due to the complexity of the children's needs.

3.78 The rationale for closing the case was that the family had moved to Newcastle and the case had been transferred.

3.79 On 14th June 2011, contact was made with Cumbria Children's Services by SW5 in Newcastle specifically to inform them that Child O was living with FCO in Cumbria whilst MCO and BCO remained in Newcastle.

3.80 No further action was taken by Cumbria Children's Services at this contact and a decision was made to review the case should the family make contact.

3.81 On 29th June 2011 a Social Worker from Newcastle CSC made contact with Cumbria CSC (SW6) to formally transfer Child O's case back to Cumbria. She was aware that practitioners in Cumbria had difficulty in seeing or engaging with Child O.

3.82 SW6 carried out a provision of advice and information and made contact with Child O's clinical psychologist in Newcastle who confirmed that she was continuing to work with Child O and FCO and was seeing Child O regularly. The clinical psychologist felt that some progress had been made with Child O and that risk had been reduced. SW6 was advised that Child O was still registered with a GP in Newcastle.

3.83 SW6 also contacted SW5 in Newcastle and discussed Child O with her. SW6 advised SW5 to make a formal referral of Child O to CSC in Cumbria which would then trigger contact with FCO and MCO to carry out an initial assessment and transfer to the learning disabilities team. SW5 agreed to discuss this with her manager.

3.84 On 5th January 2012 Cumbria CSC were contacted by the Senior Nurse, Safeguarding (SNS) in Newcastle. The SNS stated that she had worked with Child O and BCO and again confirmed that Child O had returned to Cumbria with FCO whilst BCO remained in Newcastle with MCO.

3.85 The SNS also stated that she was aware that the children had been seen by CAMHS and that a new referral to Cumbria CAMHS was to be made for Child O.

3.86 The SNS repeated that both Child O and BCO had wanted full teeth extraction.

3.87 Child O had visited a dentist in August and his teeth were in good health however the dentist had contacted the SNS on 4th January 2012 and was concerned because Child O had deliberately set about rotting his teeth by consuming litres of high sugar drinks to which he had been adding extra sugar. The dentist confirmed that significant damage had been done to Child O's teeth and that he needed 4 extractions and that his diet was generally poor.

3.88 The SNS expressed her concerns at Child O's extreme vulnerability and his capacity to make his own decisions about his diet and consumption of sugar. The SNS was concerned that FCO was not providing parental care and supervision for Child O and that this could be viewed as neglect given Child O's many vulnerabilities.

3.89 It was agreed with the Social Worker (SW7) who took her call that the SNS would make a formal referral to Cumbria CSC.

3.90 The SNS made further contact with Cumbria CSC on 1st February 2012 and repeated her concerns that Child O has a fixed belief that having his teeth removed would make his life better and that Child O had been isolated since being home educated from the age of 9. It also appeared that Child O's anxieties had been reinforced by his parents who had removed him and BCO from any situations which brought them into contact with other people i.e. situations which caused the children distress. This meant the children had missed appointments and Child O spent most of his time in his bedroom and had very little contact with others.

3.91 The SNS also described that Child O had admitted to drinking 4 litres of cola (to which he had been adding granulated sugar) each day over a period of 3 to 4 months. When he was asked Child O said he had researched how to rot his teeth on the internet.

3.92 As Child O was unable to leave the house alone it was apparent that FCO must have been buying the cola and sugar for him and possibly supported Child O in his actions.

3.93 Child O was, by then in considerable pain and had asked if his dentist could save some of his teeth.

3.94 Following this contact a further provision of advice and information was carried out (this should have been recorded as an Initial Assessment) by SW8.

3.95 FCO requested assistance to move to Carlisle as his current lease was due to expire and Child O wanted to attend college.

3.96 Child O was very quiet during this meeting and responded with ‘yes’ or ‘no’ answers or reflected FCO’s comments. His body language however was noted to be relaxed and he made eye contact. It was also noted that his teeth were very brown.

3.97 SW4 discusses assistance with housing and options for Child O to attend college. When Child O’s teeth were discussed, and when asked, FCO reported that Child O was seeing a dentist and was accepting treatment.

3.98 FCO wanted to know how SW4 and SW8 knew about Child O’s strategy of rotting his own teeth and that he had asked if his remaining teeth could be saved.

3.99 FCO reported that Child O had stopped drinking the sugary drinks and sucking lemons and had started to brush his teeth. Child O concurred with this.

3.100 FCO also reported that there had been several months delay in arranging dental appointments for Child O which had been problematic and that the next appointment with a dentist was in order to decide how to treat Child O and not to actually carry out treatment.

3.101 It was agreed that SW4 would assist FCO with a housing support letter and liaise with CAMHS.

3.102 The following issues were recorded as concerns:

- 3.102.1 Child O was not voluble which, given his difficulties and lack of social contact was to be expected.
- 3.102.2 FCO was dominant in conversations and clearly negative towards agencies.

3.102.3 Child O was allegedly refusing to engage with CAMHS at the Fairfield Hospital

3.102.4 Minutes of the professionals' meeting were not forwarded from a professionals' meeting at the Newcastle.

3.102.5 It was also noted that Child O is suffering damage to his teeth however this is not viewed as self-harm and therefore not a mental health issue by staff at St Nicholas's Hospital. In their view it is a safeguarding issue because of Child O's autistic impairment. However Child O had not been assessed as having an intellectual impairment and therefore did not have a learning difficulty. In some LSCB areas this would mean that Child O did have a mental health issue but neither Cumbria nor Newcastle CAMHS perceived this to be the case.

3.102.6 Both CAMHS had been happy to discharge Child O as he does not wish to receive their service.

3.102.7 Child O did not meet the requirement for a service from the learning difficulties team due to their threshold requirements. It was noted that if Child O did not meet these criteria it was difficult to see how he lacked capacity to make his own decisions.

3.103 The following issues were identified as positive:

3.103.1 Child O's situation has apparently changed (however there was no summary of what this change is or how it is a positive change)

3.103.2 During the meeting FCO encouraged SW8 to have direct contact with Child O. It was noted however that Child O did not answer SW8's calls.

3.103.3 Staff at St Nicholas's Hospital clearly stated that if Child O did not cooperate with mental health services he would not suffer significant risk. However they were of the view that he requires ongoing support from this service.

3.104 On 24th February a Cumbria Children's Services Social Worker attended a meeting at St Nicholas Hospital in Newcastle. The SW records indicate the focus of the meeting was legal action taken against the Health Authority (the SW records are not specific about this legal action i.e. by whom and why) Specific safeguarding concerns however included that FCO was thought to be providing means for Child O to destroy his teeth and the family's failure to co-operate with clinical services.

3.105 The last entry on CSC records before Child O's death is dated 16th May 2012 and records a contact from CAMHS. An arranged appointment was attended by FCO. He stated that Child O did not wish to attend or receive a service from CAMHS.

3.106 The SW records conclude FCO was once again withdrawing from service.

3.107 There was no further action taken by Cumbria CSC.

Child O's contact with Education

3.108 Child O and BCO attended a small village school between 2000 and 2004 (aged 4 to 10).

3.109 In 2002 the school were provided with advice and support from the Specialist Advisory Teacher, Special Educational Needs Team for literacy and skills development for Child O.

3.110 Child O also received a reading intervention programme.

3.111 In 2004 MCO and FCO removed the children from the school and registered them with another small village school where they attended for one term.

3.112 Child O and BCO were removed by their parents from mainstream education in 2005 at the age of ten.

3.113 The School Improvement Team (SIT) maintained contact with MCO and FCO between 2005 and 29th May 2009. Child O was aged 15 at the time of the final contact.

3.114 Neither child was seen by an education specialist during that period. Reports on progress were given by MCO and FCO.

3.115 This was normal practice at the time. During the period that Child O was registered as Home Educated the DCSF guidelines stated that:

- *"Local authorities have no statutory duties in relation to monitoring the quality of home education on a routine basis.*
- *However, under Section 437(1) of the Education Act 1996, local authorities shall intervene if it appears that parents are not providing a suitable education. This section states that:*
- *"If it appears to a local education authority that a child of compulsory school age in their area is not receiving suitable education, either by regular attendance at school or otherwise, they shall serve a notice in writing on the parent requiring him to satisfy them within the period specified in the notice that the child is receiving such education."*

3.116 Once provision was deemed appropriate in 2006, the family legally opted for reports of ongoing progress. This legislation has not changed. LAs cannot insist on monitoring home educators, but continue to support through partnership. (The LA does intervene where there are legitimate concerns about the suitability of provision).

3.117 On 5th June 2010 the SIT worker who had monitored Child O's educational progress via reports from MCO contacted MCO to offer support having just

learned that Child O was an inpatient at the Specialist Children's Mental Health Hospital.

Child O's contact with Dental Services

3.118 Child O's fear and obsession about his teeth was reported by MCO to have begun in 2008 and arose out of a fear that he would need dental treatment.

3.119 Child O's diet and eventually his daily routine were affected by his fear of sugar contamination and his diet became restricted. By July 2008 MCO reported that the children were checking all ingredients for sugar, cooking their own meals and using their own utensils and implements for fear of contamination. Eventually the children cooked food in a microwave in their bedroom.

3.120 On 5th February 2010, whilst still an in-patient following his suicide attempt, Child O was examined by a maxillo-facial expert who identified no tooth decay.

3.121 On 16th April 2010, MCO took Child O to visit the family dentist in Cumbria. It was reported that Child O did not require any treatment and his dentist was going to speak to a colleague in the Newcastle Dental Hospital the following week. Child O stated that he realised that he may have to wait till he is 18 (i.e. an adult) before he could have his teeth extracted and this may still not be possible. Child O stated he was not happy to wait but he understood why this was the case.

3.122 On 8th June 2010 Child O had an appointment at the Dental Hospital and was reviewed by a Consultant in Paediatric Dentistry. Child O attended with MCO and requested to have all his teeth extracted. Clinical examination revealed no carious lesions and his oral hygiene was perfect. MCO and Child O were advised against any intervention at this point in time and to continue with his routine dental health. Child O could be reviewed at the age of 18 years in regards to his request for removal of his teeth. The dentist agreed to engage with Child O'S Consultant Psychologist.

3.123 Child O was extremely distressed following this appointment because he had been told he could not have his teeth extracted.

3.124 On 1st September 2010 MCO requested that staff on the mental health unit arrange for Child O to see a dentist that had experience in dealing with patients with body dysmorphic disorder (BDD). MCO also wanted staff to look into information on the outcomes of surgical/dental interventions of patients with BDD.

3.125 On 14th September 2010 a telephone call was made by Child O's doctor to the dentist asking if there was a dentist with expertise or special interest in

patients with mental health issues and/or BDD. The dentist explained that there were dentists that do restorative work and work with patients with mental health issues but usually discussions and assessments have taken place before the procedure. A contact number for another dentist was given. The doctor spoke to the dentist 2 who explained that in most cases patients with BDD who have had tooth extractions have regretted it. It was suggested that a joint appointment was arranged with mental health input and the dentist to discuss and explain this with Child O.

3.126 A letter dated 15th September 2010 was sent to the Consultant in Paediatric Dentistry from Senior Trainee in CAMHS requesting a professionals meeting to discuss a future management plan for Child O as Child O's parents were requesting for him to be reviewed by a Dental Surgeon in regards to having his teeth extracted.

3.127 On 29th September 2010 a telephone message from the Speciality Trainee in Child and Adolescent Psychiatry was left requesting to speak to the Consultant in Paediatric Dentistry to follow up the letter dated 15th September. Two dates in December 2010 were offered by the dentist when the professionals could meet.

3.128 A meeting between the Consultant in Paediatric Dentistry and the Consultant Psychologist took place 14th December 2010. The Paediatric Dentist explained that it would be extremely difficult from a professional point of view to justify the extraction of Child O's teeth and it was therefore agreed that there was no need for a further review.

3.129 After it was made clear to him that he could not have his teeth removed until he was an adult and legally able to make that decision it appears that he set about rotting his healthy teeth in order to 'force' the extraction of his teeth.

3.130 On 12th May 2011 once Child O had returned to live in Cumbria a telephone call took place between Child O's newly allocated psychologist and dentist in Cumbria. The discussion outlined that there was no evidence of decay to Child O's teeth and that ethically the dentist could not justify extraction. It was further discussed that the dentist would see Child O within 5 days of request for appointment. Contact was made with the Newcastle consultant Psychiatrist, who was informed that a full extraction may happen when Child O reaches the age of 18 or if decay occurs.

3.131 On 6th June 2011, Child O's dentist in Cumbria received a letter from the Head of Dental Services in Leeds which advised that an individual of 17 years of age can legally consent to medical and dental treatment as long as they have the mental capacity to understand and assimilate the information

and then make a conscious decision. An individual should be made aware both verbally and in writing of the consequences of this drastic treatment.

3.132 An NTW record dated 23 November 2011 stated that Child O's Psychologist and FCO are attempting to find a dentist to carry out the extraction procedure. Initially the psychologist was informed that Child O could have this done in his local area but was then informed that there was no dentist in the area that was willing to do this.

3.133 On 23rd November the Consultant Clinical Psychologist, Northumberland, Tyne & Wear Trust (NTW) emailed the Consultant in Paediatric Dentistry stating that Child O may have the capacity to make the decision to have his teeth removed. The Consultant in Paediatric Dentistry replied via email confirming Child O is no longer a paediatric patient and will not be seen in his speciality. Child O does not require specialist intervention and can be managed within the local primary care setting i.e. GDP.

3.134 On 22nd December 2011, Child O's dentist wrote to the Clinical Psychologist to state that he had recently examined Child O who had taken a conscious decision to destroy his teeth, using soft drinks and excessive sugar uptake. Examination showed complete loss of enamel and 80% loss of mineral from dentine in his upper and lower front teeth. These teeth would only be restorable with extensive complex restorative dentistry which Child O refuses. Consequently the dentist reluctantly agreed to extract his front twelve teeth which are beyond repair.

3.135 The dentist then explained that if Child O continued to follow his current excesses his dentition will be destroyed within 1 year as the posterior teeth already showed 30% loss of coronal tissue.

3.136 The dentist ended his letter by saying that In view of this development, it may be prudent to reassess the management of Child O's desire to render himself edentulous.

3.137 Between 3rd and 10th January 2012 there was intensive communication regarding Child O's teeth between the dentist, FCO and other agencies (these are detailed in the integrated chronology) and by 10th January 2012 the dentist in Cumbria had sought legal advice and declined to offer any future treatment as his professional opinion had been disputed. There were two options for future treatment either a referral to Newcastle Dental Hospital or Specialist Implant Clinic. (The dentist referred Child O to Newcastle as this is a NHS facility).

3.138 NTW also sought legal advice about Child O's capacity and the implications of possible future litigation i.e. their own legal position.

3.139 FCO was heavily involved in Child O's contact with the dentist and was 'combative' in his communications with him.

4 ANALYSIS

4.1 As stated previously the review covers a significant period of time. Key events will therefore be analysed briefly against the terms of reference, the outcome of the learning review and research in order to draw conclusions and identify lessons learned by professionals involved in the case as well as the learning for the wider membership of the Safeguarding Board.

4.2 The following specific key lines of enquiry for the SCR are addressed in the analysis. The key lines of enquiry included:

4.2.1 How well were the risks of significant isolation recognised and understood?

4.2.2 Was the isolation of Child O (and his sibling) ever, in itself, considered neglectful or abusive?

4.2.3 How was the parenting capacity of Child O's parents assessed?

4.2.4 How well were the complex needs of Child O recognised, assessed and responded to?

4.2.5 Was a risk and need assessment carried out in respect of the circumstances of the whole family. Were there other opportunities for risk assessments which were missed?

4.2.6 How well information was shared, understood and responded to between agencies and across geographical boundaries

4.2.7 How well was Child O listened to and understood?

4.2.8 Multi-agency tolerance and understanding of risk, how do we escalate concerns?

How well were the risks of significant isolation recognised and understood?

4.3 The very nature of Child O's isolation, both geographical and social meant that he was largely invisible both to practitioners and within his community. He had little contact with universal services apart from the family GP.

4.4 The GP was aware of Child O's isolation but it does not appear that this was viewed as a possible risk or contributory factor to Child O's difficulties.

4.5 The CAHMS practitioners visited Child O in the family home and at clinic on a regular basis throughout 2005 and up to February 2006 when Child O and BCO stopped engaging because it had been suggested that they see separate therapists.

4.6 Child O's isolation was obvious at that point and was recognised as a symptom of his general distress and difficulties. There was no specific reference in the CAMHS chronology to isolation as an overarching risk factor i.e. that Child O would become invisible to external agencies and / or that isolation could be his parent's response to Child O's difficulties rather than his own.

4.7 Child O's entire family increasingly isolated themselves and Child O was not seen by any practitioner (apart from a visit to A and E for an injury to his finger) between 2006 and 2010.

4.8 During Child O's lengthy inpatient stay his home environment was recreated in his hospital room and he remained hunched on his bed for much of the time, followed intricate rituals as he cooked his meals in his bathroom and then ate alone. On occasions his mother prevented contact with practitioners and spoke on his behalf.

4.9 This situation did not appear to have been challenged or recognised as a recreation of Child O's isolation within his home environment.

4.10 The pattern of isolation recommenced shortly after Child O's discharge from hospital in 2010 despite there being an intensive management plan in place for Child O and by early 2011 Child O was rarely leaving his bedroom.

Was the isolation of Child O (and his sibling) ever, in itself, considered neglectful or abusive?

4.11 On occasion practitioners were prevented from seeing Child O by his parents who reported that Child O would not see them. MCO, and less frequently FCO, provided progress updates on home education, described Child O's behaviour, interpreted his distress and expressed his wishes to practitioners.

4.12 This did not appear to have been viewed as potentially neglectful or abusive by practitioners who recorded MCO and FCO's statements about Child O and acted upon them.

4.13 It appeared to be Child O's choice that he isolated himself from society and increasingly from his own family. The reasons for this were never explored with Child O himself after his disengagement with the CAMHS team in 2006.

4.14 Child O's apparently self -imposed isolation did not appear to be considered as a symptom of neglect or abuse but rather a symptom of his difficulties.

How was the parenting capacity of Child O's parents assessed?

4.15 There was no formal assessment of MCO and FCO's parenting capacity.

4.16 A reference to parenting was made in 2005 when, in a letter to the GP, the CAMHS practitioner mentions the need to work with the parents on parenting issues.

4.17 In 2010, the safeguarding referral which was made by the paramedics who attended when Child O attempted suicide included neglect and parental incapacity amongst their concerns.

4.18 Neither reference to MCO and FCO's parenting triggered a consideration of a parental capacity assessment.

4.19 On 26th November 2011 records of a Strategy Meeting held in respect of BCO by Newcastle Children Services outline clear concerns for both boys and identify gaps including that there had not been an assessment of either parent. There were no plans put in place for this to be carried out.

4.20 The comprehensive management plan formulated in June 2010 by the National OCD Team suggested that an urgent piece of work was begun with Child O's parents including setting up some visits to learning environments and their crucial role in the strategy to reduce the children's anxieties.

4.21 The family's history suggests that it would have been difficult, if not impossible for MCO and FCO to manage to comply with this requirement but this did not influence the content of the management plan or trigger an assessment of parenting capacity or raise any safeguarding concerns.

4.22 It was apparent within a very short time of his discharge from hospital that MCO and FCO continued to struggle to cope with Child O and BCO and they did not

comply with the management plan. Child O very quickly became isolated and disengaged from contact with practitioners.

How well were the complex needs of Child O recognised, assessed and responded to?

4.23 Child O's complex needs became apparent to the CAMHS practitioners who spent time with him during 2005 and 2006. It is unclear however what long term plans were formulated to address these needs.

4.24 The CAMHS practitioners did not share information about Child O with other agencies apart from the GP.

4.25 Once Child O disengaged from CAMHS in 2006, the CAMHS practitioners shared this information with the GP but did not make a safeguarding referral or share their significant concerns with any other agency.

4.26 The GP saw Child O on seven occasions between June and December 2007 as Child O was suffering from a gland infection. There is no evidence that the GP explored the possibility that stress was an underlying cause of the infection or that he referred to Child O's isolation and other difficulties despite the level of concerns which had been described by MCO and the CAMHS practitioners in their communications with the GP.

4.27 The GP appears to have treated Child O for the presenting issue i.e. an infection without considering Child O's other needs.

4.28 Between 2006 and 2010 Child O was not seen by any agency (other than A and E staff for an injury to his finger and the family GP)

4.29 MCO and FCO continued to attend appointments without Child O and provided progress updates on home education, described Child O's behaviour, his distress and expressed wishes on his behalf. Arguably therefore, it would have been impossible for any practitioner to recognise, assess and respond to Child O's complex needs between 2006 and 2010 as they did not see or speak to him.

4.30 One example of this occurred in 2009, 3 years after he last saw the twins and acting following reports from MCO about Child O, the CAMHS Clinical Psychologist had a telephone conversation with Child O's GP and discussed OCD treatment/medication and highlighted the boys concern regards food containing sugar. The Clinical Psychologist suggested sending the boys some information on OCD along with some questionnaires for them to fill out. Once

completed, he would arrange to see the boys with their parents regarding an approach to CBT.

4.31 It is difficult to understand how a serious diagnosis could be discussed and actions agreed between health professionals when Child O himself had not been seen.

4.32 Child O attended an appointment with a CAMHS consultant on 15th January 2010 and a trial of SSRI's (selective serotonin reuptake inhibitors – antidepressants) was to commence and a prescription of Fluoxetine 10mgs daily given. The CAMHS consultant noted that Child O (and BCO) was small and underdeveloped for their age. Given what he knew about their diet (which was had become restricted due to fear of contamination) this was a possible symptom of neglect / malnutrition. This did not trigger a safeguarding response and /or a referral back to the GP for weight monitoring.

4.33 Upon his admission to hospital following his suicide attempt in 2010 Child O underwent several assessments and plans were put into place for his longer term care and educational needs.

4.34 In June 2010 Child O and BCO were assessed in Newcastle by a Psychiatrist and Psychologist from the National CAMHS OCD Team from the Maudsley Hospital. This assessment had been requested by both NTW and Cumbria Healthcare.

4.35 As a result of the assessment a management plan was formulated. The management plan is detailed below:

4.35.1 Educational:

- the needs of the children need to be urgently reviewed by the educational authority and a plan put in place taking into account their exceptional needs and also the fact that the educational system has significantly failed them to date.
- Both children are going to need highly specialist teaching from an individual with skills in both LD and autism.
- They will require a 'Statement of special educational needs' and consideration given as to whether at some point in the future a residential placement might be the best way to try and optimise their potential.
- It is suggested that an urgent piece of work is begun with parents setting up some visits to learning environments which would need to have both experience of LD and autism, as well as offering and individualised,

nurturing curriculum. An ideal setting would be in an environment where outside activities familiar with their surroundings i.e. gardening, farming.

4.35.2 Psychological:

- It is unlikely either child has cognitive or emotional capacity to engage in conventional cognitive behavioural therapy, so the most likely route to desensitising them to their fears is a collaborative and slow programme of graded exposure.
- It is essential that this is preceded by a reinforcement of the anxiety education that has already begun. It could start by everyone talking about ordinary fear/anxiety and how normal this is. It is also important for the children to hear their parents talking about how they deal with fear and anxiety.
- This could then be preceded with very simple small steps of behavioural experiments for example looking at pictures of teeth, dental equipment or experiencing different temperature of water in their teeth and learning to rate anxiety. This work need to be done in collaboration with the family.
- For discussions, it would be important that both children are treated by the same team involving therapists with expertise in LD, autism and OCD.

4.36 Whilst this plan was comprehensive it assumed that Child O's parents had the capacity to engage with practitioners and adhere to the plan.

4.37 The plan did not articulate any underlying safeguarding concerns for Child O or suggest the involvement of children's social care services.

4.38 Child O was discharged from hospital on 4th November 2010 and plans were put into place for daily contact with him until a review meeting on 8th November 2010.

4.39 Child O was seen by multi-agency practitioners from November 2010 onwards. These contacts included an admission to hospital for Guillain Barre Syndrome in June 2011. By August 2011 however, despite several attempts to contact FCO to ensure appropriate follow up and treatment for Child O there was no response from FCO.

4.40 From late 2011 onwards Child O's contacts with practitioners were focused on his attempts to have his teeth removed and then his attempts to have implant treatment. Mental health practitioners were also focused on Child O's wish to have his teeth removed and whether or not he had capacity to make such a decision.

4.41 Child O’s presentation during this period would not have offered reassurance to practitioners that he was thriving mentally or physically.

4.42 Child O did not contribute meaningfully to the assessment of risk, his needs or any plans to meet those needs.

4.43 Child O’s family context was similarly complex, not least his relationship with his twin, however no comprehensive ‘whole family’ assessment was carried out and his relationship with BCO did not appear to have been well understood.

4.44 Being a twin can bring unique difficulties such as:

4.44.1 ‘Individualisation’ which relates to the psychological issue of identifying as an individual. For most singletons this occurs around the age of 3-4 years as they go through the "I" stage - learning to distinguish themselves from other people and things around them. Identical twins often experience this stage very differently from singletons. For twins it's not an "I" stage but instead, a "we" stage, where twins learn to distinguish only so far as "us" and "them" creating a unit style identification. Many identical twins continue to relate to each other in this way into young adulthood and find themselves identifying as "we" instead of "I" even in their adult conversation. The eventual results of this unit style identification vary considerably depending on the pair of twins involved and on the specific circumstances of their upbringing. How identical twins cope with this as they grow from childhood into adolescence depends largely on their upbringing and the circumstances they find themselves in at this potentially difficult time. It can prove helpful if twins have a pre-established separate circle of friends, so that they are known as individuals within their peer groups rather than only as a twin pair. This was not the case for Child O because of his extreme isolation.

4.44.2 ‘Intense ambivalence’-twins often have strong ambivalent feelings towards one another. They may express that they love each other beyond anyone else in the world and yet they also feel the constriction of their intensely close twin relationship. Their twin is often close to their 'ideal' companion, someone who always understands them and knows how they feel. Yet, having someone who knows them so well can be stifling, making them feel smothered. They may want to be free from the restrictions and burdens the twin relationship places on

them and yet they don't want to be apart or estranged from their twin. These opposing ideas and feelings can be very distressing and confusing.

4.45 Child O's suicide attempt in 2010 caused the relationship between himself and BCO to break down. This sudden estrangement would have been very distressing for both children.

4.46 Child O's identity as a twin, the loss of the relationship with his twin and the impact of this on his parents did not appear to have been a major consideration for practitioners who attempted to engage with Child O or plan his therapeutic needs.

Was a risk and need assessment carried out in respect of the circumstances of the whole family? Were there other opportunities for risk assessments which were missed?

4.47 There was an understanding amongst practitioners that the whole family's circumstances were complex and unusual however there was no multi-agency or single agency plan to assess the risk and needs of the whole family. This was a missed opportunity to assess the possibility of neglect or abuse.

4.48 A full risk and need assessment of the whole family was not carried out. Such a risk and needs assessment should have involved the individual and collective family members and have addressed the 'twin' attachment issues between Child O and BCO as well as their diagnosed disorders, the parenting capacity of MCO and FCO, support (including respite) needs of the parents and any possible neglect or abuse issues.

4.49 MCO in particular had sought help in coping with Child O and BCO but when this help did not appear to improve Child O's difficulties she and FCO began to withdraw from and avoid the children's contact with services. The fact that MCO actively sought help was an opportunity to carry out a comprehensive risk and needs assessment but MCO's perception of the failure of any help offered hindered relationships with practitioners.

How well information was shared, understood and responded to between agencies and across geographical boundaries.

4.50 Timely and up to date sharing of information between professionals and local agencies is essential for identification, assessment and service provision, especially where there are complex and poorly understood issues such as those experienced by Child O and his family.

4.51 There are a number of episodes of poor communication and information sharing between agencies which include the following examples:

4.52 CAMHS practitioners did not share their concerns about Child O with other agencies and effectively left the decision to engage or not with Child O and his parents at a point at which it was apparent that there was no improvement in Child O's presentation and his isolation was increasing.

4.53 Similarly Child O's GP did not share information with other agencies or raise safeguarding concerns.

4.54 In October 2010 Child O's pending discharge from hospital triggered correspondence from the hospital with services in Cumbria and in Newcastle. Confusion over who had responsibility for Child O between Cumbria Children's Social Services, Cumbria Learning Disabilities services, Newcastle Children's Service or Newcastle Learning Disabilities services led to multiple re-directions of correspondence and confusion.

4.55 In July 2011 correspondence from the Consultant Neurologist to Child O's GP advised the GP of Child O's attendance to the RVI clinic (following his hospitalisation for Guillain-Barre Syndrome) and that they had tried to follow up Child O and had left several messages on his father's mobile to contact the RVI to make an appointment but the father had not made any contact. The consultant was aware Child O had been discharged from Carlisle. The letter was copied to the father and sent to his address, and Consultant Physician at Carlisle Hospital. This was an appropriate sharing of information concerning missed appointments for a very vulnerable young person who was known to have complex needs. The GP however did not respond by attempting to contact Child O or FCO or appear to recognise that missed medical appointments for what was a potentially serious condition were a safeguarding concern.

4.56 Information provided by MCO and FCO about where Child O was living changed on a regular basis as it appeared the couple attempted strategies to separate the children and it was not clear if Child O's return to Cumbria was to be permanent or temporary.

How well was Child O listened to and understood?

4.57 There were significant periods of time, spanning many years, during which Child O was not listened to as he was not spoken to or seen by any practitioner who was able to build a trusting relationship with him.

4.58 Attempts were made between 2005 and 2006 by the CAMHS practitioners to build such a relationship with Child O but he disengaged at the suggestion that he and BCO were seen by separate therapists.

4.59 At this point, the gains in trust that had been made may not have been entirely lost and could have been re-established but MCO and FCO began to attend meetings without the children and this opportunity was lost.

4.60 Upon his admission to the Specialist Children's Mental Health Hospital Newcastle, attempts were made to engage Child O in therapeutic relationships and 'normal' social interactions upon which trust is built. There was evidence that Child O had begun to form relationships with practitioners and to engage tentatively in education and outdoor activities. These tentative steps were an indication that Child O could, in time, have felt able to speak openly about his fears, hopes and wishes.

4.61 However, MCO stayed with Child O for much of the time that he was an in-patient and often became a barrier between him and what she perceived as unwanted contact with nursing and other staff and he was discharged from the Specialist Children's Mental Health Hospital before any progress could be consolidated.

4.62 Because of this Child O did not appear to have contributed to his mental health care plans.

Multi-agency tolerance and understanding of risk, how do we escalate concerns? Was there a trigger?

4.63 Neither the GP nor the CAMHS practitioners appeared to recognise the risks to Child O of extreme isolation, possible neglect and parental incapacity.

4.64 A safeguarding referral would have been appropriate from as early as 2005 onwards as it became apparent that Child O and BCO had extremely complex, poorly understood needs and vulnerabilities and that their parents were struggling to cope.

4.65 Child O undertook several assessments during the time he spent in hospital however these assessments focused on diagnoses and capacity rather than safeguarding / risk. Lack of recognition of possible neglect, consideration of abuse, fabricated or induced illness and extreme isolation did not inform any of the assessments or subsequent plans for Child O.

4.66 Child O's parents disguised compliance with the comprehensive management plan formulated by the National OCD Service was not recognised as a risk factor and within days of his discharge the management plan was not adhered to.

Learning Themes and Associated Challenges to Cumbria and Newcastle LSCB and Partners

5.1 There were indications that MCO and FCO were struggling to parent Child O (and BCO) and yet this was not responded to with a co-ordinated 'early help' offer. The fact that the children were twins should have been an important consideration for every practitioner who came into contact with family in terms of the impact of parenting twins and the impact of 'being' a twin on Child O and BCO.

How will LSCB partners ensure that practitioners and supervisors understand and respond to the needs of 'twin families' and to children and young people who are twins?

5.2 The extreme social isolation/ home education of Child O were not recognised as a risk factor.

How will LSCB partners ensure that practitioners recognise, assess and respond to the possible safeguarding implications for children and young people who are home educated?

5.3 Child O was invisible and his voice was not heard.

How will LSCB partners ensure that children and young people are seen and spoken to by practitioners on a regular basis (to be specified and agreed as part of a child or young person's plan)?

5.4 Parental factors including neglect, disguised compliance or fabricated or induced illness were not given full consideration by multi-agency or single agency professionals.

How will LSCB partners provide assurance that practitioners and supervisors recognise, understand and respond to neglect, disguised compliance and fabricated or induced illness?

5.5 Child O and his family were unique and presented practitioners with several challenges and they did not always know how to respond to Child O as (a child and later as a young person) or to his family.

How will LSCB partners ensure that practitioners and supervisors are enabled and encouraged to proactively seek to discuss cases, share information, and give and receive support to and from multi-agency colleagues in their work with families or individuals?

5.6 Child O and his family moved between geographical areas and between service 'areas'. This caused a loss of focus on Child O as a child in need and a child at risk and an increased focus on service criteria and geographical 'responsibility'.

How will LSCB partners ensure that children and young people who do not neatly fit service criteria do not 'bounce' between services and/or geographical areas?

5 CONCLUSION

6.1 During the course of the Learning Event practitioners who had contact with Child O and his family considered the key lines of enquiry and attempted to describe what 'good would have looked like' for Child O. They identified that with hindsight certain actions could have been taken or done differently to safeguard him and in some agencies since November 2012 practice has changed, although not entirely as a result of this case.

6.2 Child O was a very vulnerable young person with complex and poorly understood needs and associated risk factors.

6.3 Child O's tentative engagement with certain practitioners prior to and during his admission to hospital demonstrated that he was capable of accepting support, however he was, on the whole, an extremely withdrawn and hard to reach young person. Attempts to engage Child O were also hampered by his parents in their attempts to protect him from distress and minimise difficult behaviours in the home. However, Child O may have responded well to a long term multi-agency care plan which included intensive family focused therapy.

6.4 Child O had identifiable emotional, mental health and educational needs that should have resulted in multi -agency planned and coordinated help from as early as 2005.

6.5 Child O's parents asked for help in coping with Child O and BCO and they and Child O himself did not feel that the help and support they were offered by agencies improved Child O's distress or behaviour. Consequently, Child

O's parents' relationship with practitioners became distrustful and difficult on occasions.

6.6 Child O's parents attempts to reduce his (and BCO's) distress and manage his behaviour may well have had unintended negative consequences which compounded some of Child O's difficulties.

6.7 Child O's parents withdrew Child O, BCO and, to an extent, themselves from their community and the children's behaviours, rituals, anxieties and compulsions appeared to dictate family life in their remote home.

6.8 It was clear upon listening to the practitioners who participated in the learning event that contacts with Child O and his family caused much consternation and there was a real sense that practitioners, individually and collectively, had been at a loss when trying to make sense of what they were presented with. This led to an over reliance on assessment and diagnosis of disorder or potential disorder (i.e. if we know what 'it' is we can then treat or manage 'it') rather than a holistic consideration of Child O's lived experience within his family and home environment.

6.9 The multi-agency meetings which were held to discuss Child O during the time he spent in hospital did not appear to give practitioners the opportunity to reflect upon Child O's lived experience, his daily life within his family environment, or consider wider safeguarding concerns beyond his suicide attempt.

6.10 It is also apparent that many practitioners who came into contact with Child O also struggled to engage him in meaningful dialogue let alone therapeutic intervention or educational opportunities. There were small signs that Child O was making some progress whilst he was still an in-patient at the Specialist Children's Mental Health Hospital but these were not sustained and were in part hampered by MCO in her attempt to minimise Child O's distress by managing his environment in the hospital ward.

6.11 His various (sometimes conflicting) assessments and diagnoses tell us very little about what Child O was like as a person. However, we do know that he liked horses and being outside, we know he was very capable at using the internet to carry out research, we know from different practitioners accounts that he could be 'charming', we know that he had strength of will and that he was able to formulate strategies to achieve his goals (even if these were sometimes harmful).

6.12 On occasion, Child O's 'voice' was heard (even when he was silent this was understood as a manifestation of his pain) but these were rare and fleeting connections and he was unable to see beyond his obsession and anxiety about his teeth to be able focus on and communicate his longer term plans and wishes.

6.13 On the whole however, Child O's voice was not heard and his relationship with his twin, his daily lived experience, his distress, his wishes and his fears were mostly communicated to others by his parents and there was an alarming acceptance of this by practitioners.

6.14 Above all it is Child O's distress and his isolation within his community and ultimately within his own family, especially in his relationship with his twin, which has been tangible throughout this review.

6.15 In summary, whilst Child O's circumstances are unique there are several themes from this serious case review which provide valuable learning for other cases. These should be considered by the relevant agencies in order to inform their practice development. For the LSCB these should inform the Board's practice development agenda.

6.16 It is therefore recommended that these themes and the challenges they present are considered by the LSCB as important learning and that specific plans are put in place to disseminate the learning amongst relevant LSCB partners.

6 REFERENCES

1. Working Together to Safeguard Children 2013 pg. 15 & 17.
2. Department for Education guidance on information sharing 2008